



Blood & Bones:  
Living with  
Cancer

Tom Corby



# Blood & Bones: Living with Cancer

Tom Corby

An exhibition at The Street Gallery  
University College Hospital, London

29th February - 24th April 2019

Curated by Marquard Smith & Rishi Das-Gupta

Number / 100



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## **Preface**

Guy Noble

Patients are constantly done to: They are prodded; poked; jabbed; cut; stitched; scanned; sedated; irradiated; incubated; plastered; moved; wiped; lifted; fed and watered. In so doing patients increasingly become a passive part in their conveyer-belt of care. This can be dehumanising, the illness taking central stage and the person forgotten. The arts in hospitals, however, can help us to remember the whole patient. They provide us with support and nourishment for the soul, but in doing so, they can also provoke, and ask difficult questions of us and in so doing help us to make meaning of our lives. The arts can also challenge the medical establishment, giving patients a voice and a way of expressing their experience of living with illness. Tom Corby's exhibition *Blood & Bones: Living with Cancer*, on display in University College Hospital, London, does exactly this. He uses his personal data collected whilst on this conveyer-belt of care to offer an alternative portrait of living with cancer. He re-interprets the methods used for collecting and visualising data into a personal narrative that offers a shared perspective and language of illness and recovery.

Artists working within hospitals or in response to illness generate essential questions around the fallibility of the human condition. Tom's work is no

exception. Artists can help to reconcile illness and disease as a normative part of being in the world. The self-portraits from the 1980s of Scottish artist John Bellany RA for instance, depict him in a hospital bed, tubes attached convalescing from a liver transplant, an ill man in the balance of life and death, fighting for recovery. It might be then that art can be used, as artist Grayson Perry once said, to face 'up to the realities of being stuck in a fallible body', and in so doing contribute to the healing process.

UCLH Arts and Heritage is pleased to be able to host this exhibition and partner on this catalogue and associated talks to engage the public in order to open up a conversation about illness, and the realities of living with cancer. UCLH Arts and Heritage is committed to providing a welcoming, uplifting environment for all patients, visitors and staff through the use of a varied and stimulating arts and heritage programme. Its work aims to improve the patient experience, boost staff morale, increase engagement with the arts and celebrate the Trust's unique heritage and community. UCLH Arts and Heritage is the hospital arts project that serves UCLH NHS Foundation Trust and its surrounding community and is funded entirely by charitable donations and fundraising.

## **What will it be like?**

Rishi Das-Gupta

Clinicians spend much time understanding disease and one of the first things we learn is that the course of each person's illness is different and their experience of similar diseases varies dramatically. Often, buried within the question 'how long do I have?' is the deeper question 'what will it be like?' Many people choose to discuss with others who have had a similar disease or undergone a similar treatment to understand better what to expect. However, the limitation of sharing individual stories through conversation is that we tend to focus on the highs and lows of the journey. Getting a perspective on the whole route taken is often a challenge. Prof. Corby captured personal data on his experience of cancer and its treatment. The presentation of his experience in this exhibition offers an opportunity for us to engage with his subjective experience presented through objective data as art. I hope that it sparks conversations about how we perceive illness, treatment and recovery.

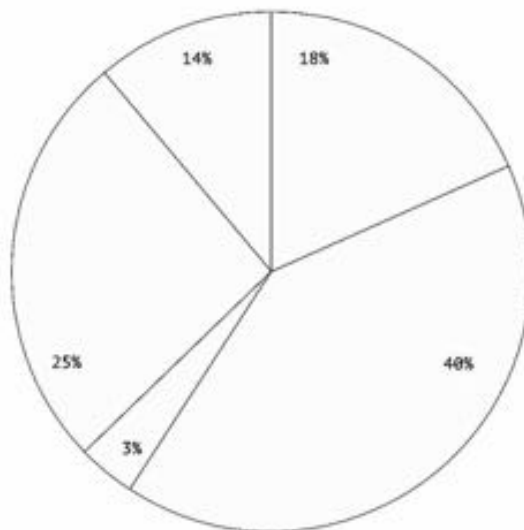








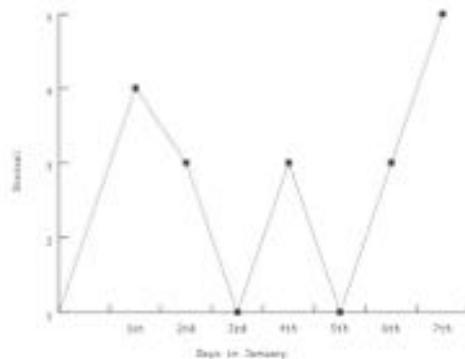
### Stoicism for February



I Feel Fine = 18%  
Grin and Bear it = 40%  
Stiff Upper Lip = 25%  
Wobbly Lip = 14%  
Illness What Illness = 3%

The percentages breakdown are interesting compared to mood and suggest that while my feelings about things are affected, my resilience or ability to cope is good. 40% of the time I'm happy to Grin and Bear it; 18% of the time I Feel Fine; 25% of the time I stiffen my lip. Of course all sorts of interpretations can be made including that I suffer a complete inability to face my plight. I prefer to think I'm stubbornly good at coping though.

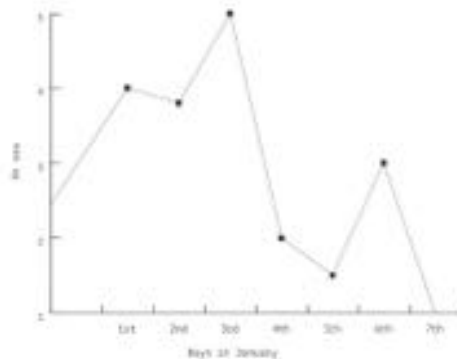
Statute Index 1st week of January



Statute Index

Disney what. Stines = 6  
 2 Feet. Fine = 5  
 Ochs and Bear is = 6  
 Ollie Upper Life = 5  
 Whip Up = 2  
 2 Derr's Mouth to Talk About is = 1

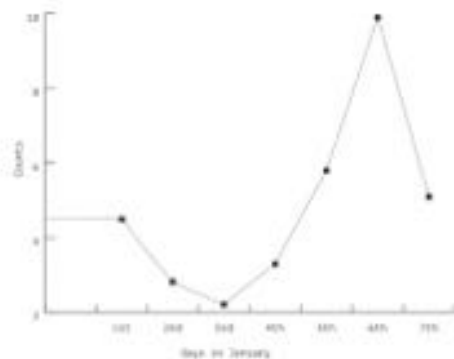
ALL at Sea Index 1st week of January



ALL at sea Index

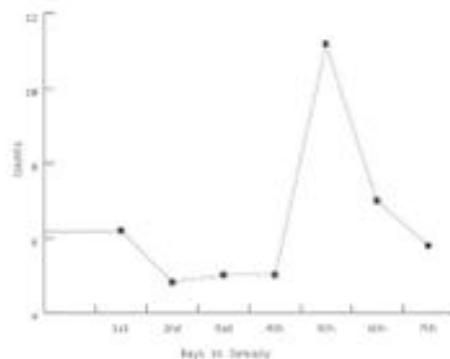
Swelled = 1  
 Puffed = 4  
 Nodded = 1  
 Yielding = 2  
 Brown = 5

Neutrophil Counts 1st week of January



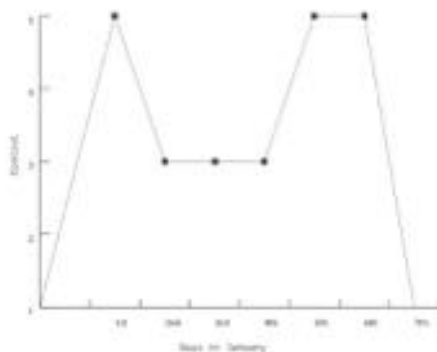
Neutrophil counts normal range = 2-7.5

White Blood Counts 1st week of January



White blood counts normal range = 3.8-9.8

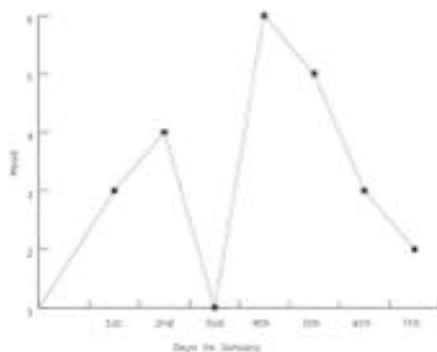
Control Index 1st week of January



Control Index

Complete Control = 10  
 A Good Deal of Control = 8  
 Some Control = 5  
 A Little Control = 3  
 No Control = 1

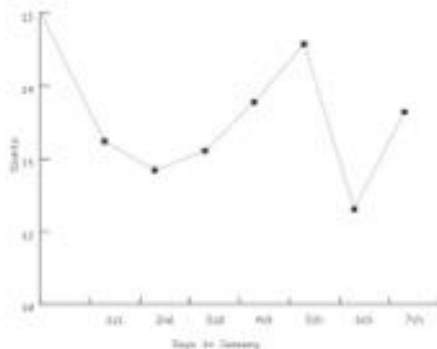
Mood Index 1st week of January



Mood Index

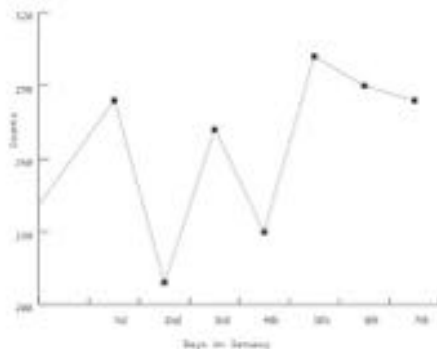
Cheerful and in Good Spirits = 6  
 Reasonable Spirits = 5  
 Felt Calm = 4  
 Felt Subdued = 3  
 Low Spirits = 2  
 Unpleasant = 1

Humor Index 1st week of January



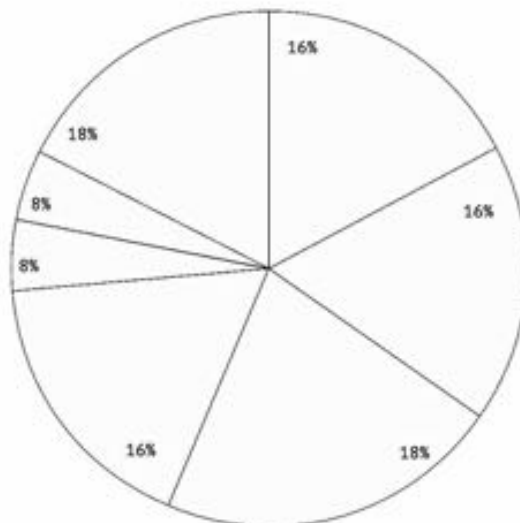
Humor Index normal range = 17.8-18.8

Flattest Index 1st week of January



Flattest Index normal range = 210-230

Hats frequency February



Beenie Striped = 16%  
Beenie Green = 16%  
Trilby = 18%  
Blue Beat Mod = 18%  
Sindhi Topi = 8%  
Bucket Hat = 8%  
No Hat = 16%

Blue Beat Mod and Trilby are both at 18% this month. The Sindhi Topi was a recent addition so scores low but is not a reflection of preference. For 14% of the time I didn't bother with a hat which covers the period before my hair fell out. My recollection is that this was a rarer occurrence than it actually was. The data in this instance works against my subjective memory.

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## **Blood and Bones**

Tom Corby

'If I'm going to have to be ill,  
I may as well do something interesting with it.' (1)

I found out I had cancer (multiple myeloma) in 2012 after suffering pain in my shoulder. I had never been seriously ill before and my only previous contact with hospitals of any kind was as a visitor. The moment of diagnosis is fearful, vertiginous and sobering as your immediate horizons shrink from 'four score years and ten' to what could be a handful of months punctuated by unpleasant medical treatments. As an artist my immediate response was to explore my illness as a problem that could be examined from different perspectives, reflected upon, and ultimately captured in some form. How do you even represent such a thing? Where do you begin when faced with such an excess of feeling and disorientation?

'Stoicism: Grin and Bear it = 7'

'Control: A Little Control = 4'

'White blood cells: 3.84'

'All at Sea: Nonplussed = 3'

'Hat: Striped Beenie'

As a new patient you are introduced to a world of tests and results, 'gridded-up', pricked, measured, scanned and cut; someone will literally 'take the piss'. These testing regimes are of course vitally important as diagnostic and predictive processes but as a result you become an administrator of your own illness, being ill is a full-time job and the time you spend dutifully recording your results liaising with hospital administrators and medics is significant. In my world, these daily, weekly and in some instance hourly processes of data extraction, took on a significance beyond the statistical or diagnostic, akin to something fetishistic, magical, and symbolic of wider bureaucratic and pathological forces at the limits of my comprehension. They could also generate moments of humor and enabled points of connection with other staff, patients and family members.

'All at Sea: Bewildered = 5'

'Mood: Felt Subdued = 5'

'Pain: Moderate = 3'

'Haemoglobin: 14.3'

'Hat: Blue Trilby'

What these data regimes are, how they enable connection and communication, and how they can be turned to narrate and document the lived experience of a traumatic event are at the heart of this project.



Following diagnosis I designed a range of methods to track and measure my illness. Alongside my normal blood, pain and other bio markers, I invented or adapted a range of other data indexes through which I could keep track of and communicate my experiences including: 'stoicism trackers'; the 'all at sea index'; 'control', and 'mood' amongst others. Each of these produced a numeric score which was output in graph or other visual form and published regularly on a project website (bloodandbones.org). I also kept a running total of the drugs I was consuming and their costs derived from an NHS procurement database. Finally, I formulated a 'sartorial tracker' that captured my daily change of headwear as I had begun to wear hats as a result of chemotherapy side-effects.

This way of combining personal, psychological, medical and financial data enabled me to triangulate the complex sets of feelings, experiences, emotions and moments which people experience when undergoing treatment into a 360° view, a process that also enabled a daily practice to help me structure and make sense of my days. Beyond this therapeutic conceit lay a more ambitious objective to contribute new languages and expressions of illness from the perspective of an 'artist-patient'. I hoped some of the approaches I developed, which I called 'data documentary', would be helpful and re-usable by others, and published all my data and methods on the project website.

'Stoicism: Grin and Bear it = 5'  
'Mood: Felt Calm = 6'  
'Control: Some Control = 6'  
'Hat: Blue Beat Mod'  
'Serum Electrophoresis: No Paraprotein Detected'

There has been some very good work by other 'artist-patients' exploring their cancer, notably by Jo Spence who in the 1980s documented her breast cancer using photographic practice to interrogate power imbalances in relationships between medical institutions and patients, and Kathrin Spielvogel who in the 2000s used film montage techniques to image her feelings of disjuncture whilst under treatment. Much has also been written on the subject, and after diagnosis I returned to Susan Sontag's *Illness as Metaphor* (1978) in which she proposes that cultural renderings of the disease can be as damaging as the pathologies they represent. (2) Metaphors, Sontag argues, introduce an obscuring layer to our understanding of cancer at the expense of more measured accounts and understandings of the social and medical reality of treatment. These arguments are insightful, but as argued by George Lakoff and Mark Johnson in their book *Metaphors We Live By*, it is difficult to escape metaphor as it is structurally embedded in our language ('structurally embedded' *is itself a metaphor* (3)). Their approach, sought a way to respond to Sontag's requirements for more nuanced accounts of disease

but which also gave free rein to include the personal and emotive voice of lived experience. In my images presented in this 2019 exhibition at University College Hospital's The Street Gallery on Euston Road, and in this accompanying catalogue, the arrangements of data, number, image and object develops a deliberately terse visual and informational grammar that seeks to capture both the bureaucratic mundanity of coping with serious illness and the excess of feeling such situations produce.

'Weekly Drug Consumption'

'Velcade 3.5mg vial injection: cost: £762.38'

'Lansoprazole 14 mg tablets: cost £0.46'

'Co-trimoxazole 6720 mg tablets: cost £1.76'

'Aciclovir 4200 mg, tablets: cost £03.12'

'Allopurinol 2100 mg, tablets: cost £0.26'

'Domperidone 560 mg, tablets: cost £03.47'

'Total drugs cost for this week: £771.45'

Thank God for the NHS.

★

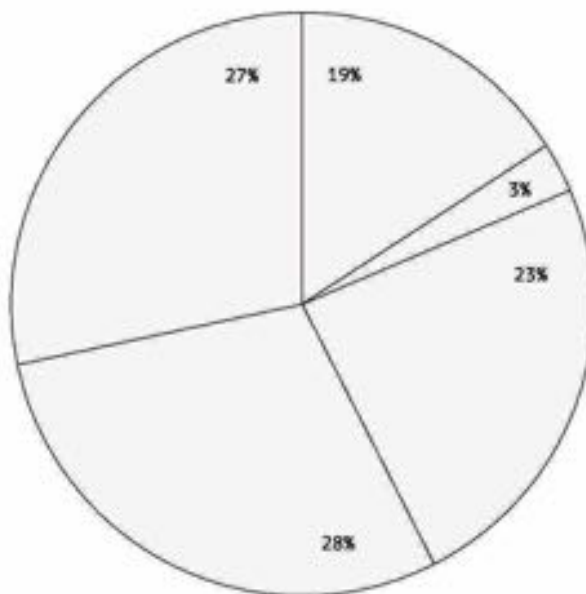
1. From my online diary, January 2013 (<https://bloodandbones.org/data/>)
2. Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors*, London: Penguin, 2009.
3. George Lakoff and Mark Johnson, *Metaphors We Live By*, Chicago: The University of Chicago Press, 1980.







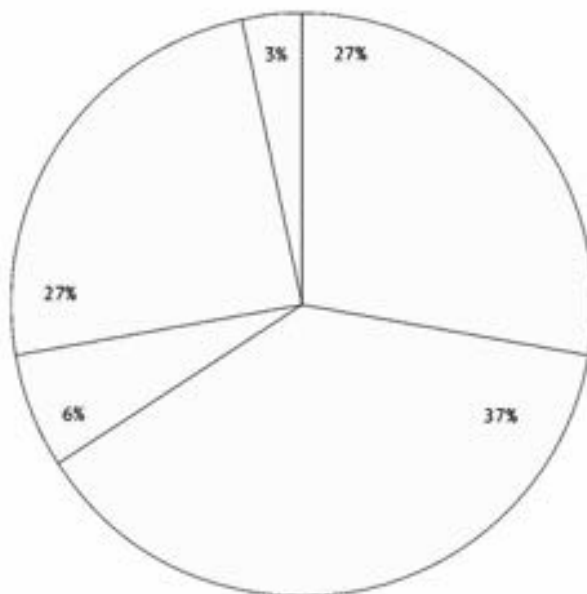
### Stoicism for March



I Feel Fine = 23%  
Grin and Bear it = 28%  
Stiff Upper Lip = 27%  
Wobbly Lip = 19%  
I Don't Want to Talk About it = 3%

I was able to Grin and Bear it for 28% of the month and I Felt Fine 23% of the time. My Stiff Upper Lip jutted out less often wobbling at 23%. Similar to my mood indexes I appear to be coping with rises in positive markers.

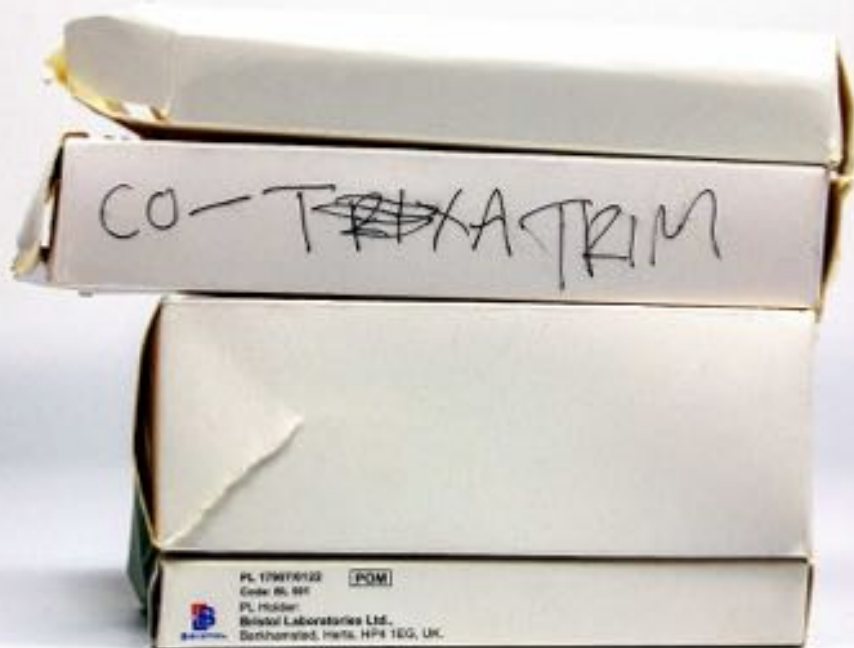
### Hats frequency March



Beenie Striped = 37%  
Beenie Green = 3%  
Beenie Patterned = 6%  
Blue Beat Mod = 27%  
Bucket Hat = 27%

The Striped Beenie was the hat of choice this month which is strange as I have no strong feelings about it although it is comfortable to wear after chemo induced hair loss. It has also been cold and it's a good hat for the strange climate change adjusted spring we are suffering. The Bucket and Mod hats were worn roughly a quarter of the time each the latter being a good option for evening wear.









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## **An Exorcism**

Agnese Reginaldo

'To really see the state of things is lethal.  
It's safer just to see what we can bear.  
Exhausting being fear-struck; howling, weak-willed.  
Much nicer to be bathing in the glare.'

*Fine, thanks!* Kate Tempest

Can we better understand what is happening to us through analytically mapping and tracking our feelings?

Emotions exist to be experienced and felt. The worst thing that can happen to us is to live our lives emotionlessly, or to live without expressing those emotions. If we let feelings flow into our minds, dance in our bodies and ache our souls, we may find clarity. 'A willingness to express negative emotions, such as anxiety or fear, can promote better relationships, greater intimacy, and more support from others'. (1)

We have words that express feelings, states of mind and conditions, but we rarely make use of them.

These are words that remain silenced.

As a child, I remember people gloomily talking about 'A Malatia', referring to cancer. 'A Malatia' is a term in Neapolitan dialect whose closest translation into English would be 'The Disease'. I wondered about the nature of 'The Disease', picturing it as a sort of life's mystery for which treatment is ineffective. Some other people, I remember, used to - and sometimes still do - refer to cancer as 'The Monster'. The word 'cancer', dreadful and serious, is tacit and tends to be 'awash in significance'. (2)

*Blood & Bones: Living with Cancer* reflects both the clinical and the social imagery of the disease. It is a project that dismisses metaphor, showing and sharing instead with a candid eye, what it means to live with cancer. From private to public, intimate to clinical, Corby's work follows broken narratives that include both polarities; warm personal feelings contrast with dry medical reports providing the base for thought-provoking conversations on the subject.

The exhibition is an invitation to talk openly about patients' experience of cancer in order to improve collective knowledge of this not fully understood and deadly disease. This is what the public engagement programme of *Blood & Bones* wants to support. Building on the artist's honest experience of cancer, this programme aims to provoke a collective,

empathic response in its audience. Contributions from patients, carers, clinicians, historians and artists keen to share their experiences and expertise, helps extend the reach of the content of the exhibition beyond the gallery space.

The exhibition is a manifestation of Tom Corby's practice that lends itself to interpretation, being a witness but also an agent of transformation from conceptual experience into physical form. It embodies personal feelings that resonate empathically with others' experiences. The public engagement programme emphasises the blurred line that separates the private from the public realm. It makes us reflect on different ways of sharing knowledge, practices, realities and feelings that can ultimately enable us to better understand the nature of cancer and how to live with it. Curating the programme of activities for *Blood & Bones: Living with Cancer* feels like diving into an ocean of wisdom, experiences and strength, with the aim of drawing attention to the practice of sharing as a coping strategy to the social and emotional isolation associated with the disease.

★

1. Graham., Stephen M.; Yang, Julie Y.; Clark, Margaret S.; Helgeson, Vicki S., 'The Positives of Negative Emotions: Willingness to Express Negative Emotions Promotes Relationships', *Personality and Social Psychology Bulletin*, 34/3, 2008, pp394-406.
2. Susan Sontag, *Illness as Metaphor and AIDS and Its Metaphors*, London, 2009.

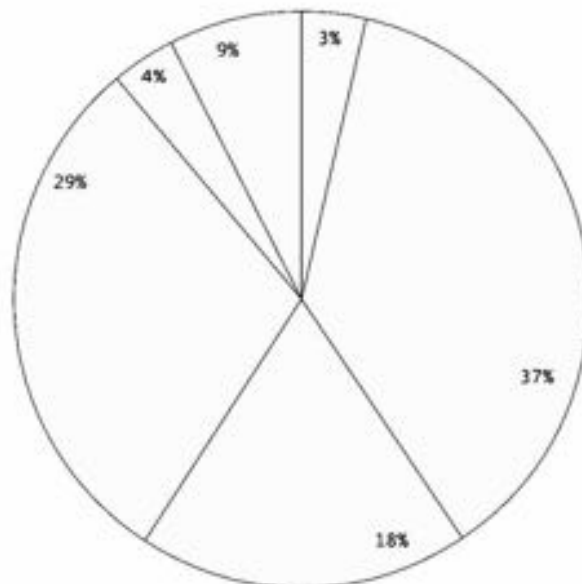








# Mood in April



Cheerful and in Good Spirits = 3%  
Reasonable Spirits = 9%  
Felt Calm = 37%  
Felt Subdued = 18%  
Low Spirits = 29%  
Sad Tearful = 4%

While on the whole I was relatively calm, my low feelings swamped my positive moods this month. I was also subdued 18% of the time. I thought I'd been coping better, but I suppose it's not surprising when you've been told you've got incurable cancer, you've lost your hair, and you've got chemo nausea. The weather hasn't been great either.







## **Human Resources**

Marquard Smith

*Blood & Bones: Living with Cancer* is an exhibition of work by internationally exhibited and award-winning artist Tom Corby.

Corby's stark, compelling, and poignant images combine 'quantitative' medical/clinical data describing his Multiple Myeloma with 'qualitative' data generated by the profound yet so often under-acknowledged power of the everyday, the experiential, the anecdotal, and the affective.

By way of such images the exhibition aspires to empower patients as individuals to take ownership of their personal medical data creatively thereby enabling them to better control and enrich the day-to-day experience of living with cancer.

The exhibition is at University College Hospital's The Street Gallery on Euston Road, London, and runs from 29th February - 24th April 2019. The Gallery is open 24 hours a day, and is a marvellously 'compromised' space because of its location in a public environment: a hospital's busy thoroughfare. Thus its audience - largely hospital patients, their families, friends, and carers, along with nurses and porters and clinicians - have no choice about seeing it. Given such impact - in terms of both sheer

numbers (it has an annual footfall of 100,000) and its potential to unsettle emotionally - the Gallery needs to be curated sensitively. (1)

If the Gallery is 'compromised' - which is to say that it is not a white cube whose interior architecture is designed primarily to shape an art experience - its audience is justifiably preoccupied: they're in a hospital, walking down the 'street' haltingly or with intent, waiting outside the pharmacy for medication, pausing to interrupt the remorseless intensity of it all, even just for a moment. Who can blame them. Understandably distracted, they may well be oblivious to Corby's images, or they may choose to look away. But if they decide to look, even askance, they will see that in these images the artist has developed a range of simple data driven approaches to track, share and make sense of his haematological cancer that might interest them.

Corby's images capture both the clinical *and* personal experiences of the physical, emotional, and affective impact of living with cancer as a patient, artist, and human being that'll surely resonate. That's because *Blood & Bones: Living with Cancer*, so engaged with issues at the heart of UCLH's mission and the concerns of its patients, presents different ways to represent the subjective experience of someone suffering from illness, providing various entry points for individual audience members to engage the exhibition theme. For example, some photographs are of the



types of head-ware patients wear while undergoing chemotherapy. Others use the visual language of data visualization and medical graphing, but are here deployed (often with tragi-comic intent) by the artist and used to articulate personal rather than medical data, thereby exposing the impulse to quantify driving so much data visualization. Still others document drug regimes, and the financial data (i.e. the cost) of the treatment (to us, the taxpayer, by way of the National Health Service). In all this, the works in the exhibition are connected to - but I believe extend beyond - the popular use of personal narratives/blogging to discuss illness in ways that are often moving, funny, informative, and therapeutic.

In sharing his data by way of these images, Corby has sought to demystify the experience of serious illness by drawing attention to the multiple experiences of the everyday, many of which are seemingly inconsequential - and certainly all too often overlooked - that can and need to be shared between patients, their families and clinicians, in order to contribute understanding to what he calls 'the ecologies of treatment [in which] patients, diseases and medics are entangled'.

★

We might believe that thinking about the human body as a data-storing resource and data-generating machine is a reasonably recent

phenomenon, born in our Age of Bio-Information, yet the idea of the human being interpretable (and utilisable) as a site for knowledge - of data extraction - goes back thousands of years. The human body has always been a resource from which to draw. (2) We are in fact always already a human resource. (3) Through a whistle-stop tour of the history of anatomy for instance, we learn:

- that the Greek Herophilus (330-260 BCE), known as The Father of Anatomy, who plied his trade mostly in Alexandria, Egypt, with his young contemporary Erasistratus was the first to perform dissections on human cadavers in order to study and learn about the workings of the human body, including the brain, eye, liver, reproductive organs, and nervous system. (4)

- that the *Hippocratic Corpus*, and later Galen, gathered medical texts that form the basis for understanding the functioning of the organs for all medical writers and physicians until the 16th Century.

- that from the Renaissance and on into the Enlightenment, the 16th Century figure of Vesalius, the founder of modern human anatomy, in challenging and discrediting Galen gives us a new account of human anatomy founded on the empirical evidence gleaned from his 'hands-on' observations of dissecting corpses himself, and, in doing

so redefines the body as a site of anatomical knowledge. (5)

- that the 'scientific research' of the 19th century (in the form of the data gathering practices advanced by Adolphe Quetelet with his codification of statistics and invention of the body mass index; Frederick Winslow Taylor with his scientific management/time and motion studies; Alphonse Bertillion with his anthropometry; and Francis Galton with his interest in data measuring 'sciences' such as biometrics, psychometrics, evolution, and ultimately eugenics) together gave us the idea of the human body as a machine, as a human motor, as part of a wider 'efficiency' drive to generate and manage (to supposedly 'improve') the human as a productive and re-productive citizen of mechanized industrial capitalism, nation, and Empire.

- that the 20th century took us from the emergence of eugenics to the 'discovery' of DNA, and up to the late 20th century's draft of the fully sequenced human genome, the 'book of life' which functions as an archive, stored in databases, and accessible on the Internet. It is in the 20th century that the human's 'productive capacity' as bio-medical is fully grasped, and it seems inexhaustible: hence the human's 'generation' of patentable entities (including biological products and genetically modified organisms), and the anticipated developments

in medicine, biotechnology, and treatment and disease management that will keep Big Pharma busy for years to come.

- and finally, that the 21st Century has refined this idea of the human to the point where we think of it as a bio-informational, data rich, genetically harvest-able resource that is itself genetically programmable by way of artificial intelligence.

This most recent iteration of the human as data dovetails with the idea of the human as metadata, a speculative proposition made flesh by way of NSA/GCHQ conducting so-called 'pattern of life' analyses of our data and metadata, so they can track us, monitor us, and know us, so that our very identity comes to be not so much understood as actually *constituted* by and as data and metadata patterns. (6) Such a proposition is now all the more palpable because of last year's Cambridge Analytica scandal, and this year's controversies over Google, Facebook et al as paragons of surveillance capitalism by which, according to Shoshana Zuboff, such digital services 'claim[] human experience as free raw material for translation into behavioural data... declared as a proprietary *behavioural surplus*, fed into advanced manufacturing processes known as "machine intelligence", and fabricated into *prediction products* that anticipate what you [we] do now, soon, and later'. (7)

What these recent events do is make more explicit what has been true for hundreds of years: the human body is not a temple, it is a data factory; we are producers, not consumers. We are a data-rich bio-medical resource: genetic, cellular, molecular, bio-informational, encoded, archival. We are bio-computational searchable, data-storing, data-generating, data-distributing machines. We are an archive and a source, or perhaps better (or worse), we are constituted as advanced information management systems (a collective bio-techno-archivo-body politic) that are in numerous fascinating and disturbing ways ripe for data extraction, utilisation, capitalization, harvesting, and monetization.

★

Dystopian in the extreme, there is a more upbeat way of thinking about this idea of the human body as a data-storing resource and data-generating machine. Firstly, generating and using medical data obviously helps to improve public health services and health care, and identify patterns of disease, which could lead to more effective practices for prevention. Secondly, and of particular relevance here, patients tracking their own data (or self-tracking, as it is known) offers new forms of knowledge about our body, its functions and behaviours, and renders our moods and emotions legible in ways that enable us to reflect on ourselves, care for ourselves, and share our needs with others. (8)

This is the right time, then, for an exhibition such as Tom Corby's *Blood & Bones: Living with Cancer* because of the increasing number of people living with cancer, and because of the importance of data as a contemporary form that mediates and shapes our lives; and nowhere is this more important than in medical science. And, while there is widespread understanding of the transformative role that data can play in contemporary medical practice, there is less work on or insight into how patients can transform and articulate their experience of their illness through personal data practices. As such, our exhibition and its accompanying public engagement activities at UCLH, the Wellcome Collection, UCL, and elsewhere respond to urgent demands from a range of perspectives to develop such new cultural expressions of illness and forms of knowledge that truly reflect the patients' experience.

Recent years have seen the emergence of technologies and platforms enabling us as individuals to chronicle – collect, analyse, and display – our own data. (This information comes from smart phones, mobile apps, GPS trackers, and scientists, including clinicians.) And Corby's work in this exhibition utilises such data as inspiration and challenge to explore the role that this data, especially personal data, plays in the lives of patients living with haematological cancer. To this end, by way of these images Corby seeks to:

- identify existing and develop new creative approaches to data's use that foreground a patient's perspective as expressed through 'personal' data-collection activities (i.e. self-tracking) including tracking emotional, affective (e.g. mood apps), and other personal responses to treatment.
- highlight and expand the ways patients might use their personal data creatively to reflect upon and make sense of their medical treatment.
- seek insights into how such creative expressions can inform wider clinical understandings of patients' experiences.

Corby's *Blood & Bones: Living with Cancer* as an exhibition enables a patient's voice to be heard. And, we believe, such processes of self-documentation and expression through personal data collection offers potential therapeutic benefit through the sharing of a patient's experiences with their families, friends, carers and medical practitioners, helping everyone better comprehend that experience.

As such, we hope to demonstrate that patients can be knowledge-producers outside of normative clinical practice; and that such practice will support clinicians in their thinking about the care of patients with

individualised experiences. Further, we look to attract the public interested in the raised awareness of the experience of haematological cancer, representations of the illness, and uses of data to express personal experiences.

Living with cancer is always personal. This may well 'only' be Tom's personal experience, and 'only' his representation of his illness, but I believe his way of taking ownership of his medical data in ways that are empowering to him is... generalizable, and I can imagine 101 ways it can be replicated by plenty of other individuals with their own circumstances, interests, curiosities, and preferences with regards to their choice of crafting activity; whether it's drawing, photography, making movies, knitting, keeping a diary, blogging, and so on.

By way of *Blood & Bones: Living with Cancer* as the first UK-based exhibition of Corby's project, we thus hope to:

- empower patients as individuals to take ownership of their personal medical data creatively, and facilitate their own cultural responses to their illness, 'giving them a voice', thereby enabling them to better 'control' and 'enrich' the day-to-day experience of living with cancer.
- empower carers, because increasing the ways patients might



generate their own representations and articulations will diversify how 'the experience of illness' can be communicated to families, friends, medical practitioners, and the public.

- privilege patient 'experience' (and how it is owned, validated, and distributed), and privilege such experience *as knowledge*, since foregrounding how personal data generation processes (as a mode of expression) can act as a palliative to the dominance exerted in representations/discourses of cancer by institutions, experts, and mainstream media organizations can change those representations/discourses.

In all of this, by way of *Blood & Bones: Living with Cancer* we aspire to change the debate on health and illness by harnessing 'personal data' as a means of challenging this privileging of expert opinion over patient knowledge and experience. We believe that such patient-led activities by non-academics changes long-term the clinical and cultural discourse of how to more productively enable a cancer patient's voice to be heard, thereby enriching dialogue on such vital but often unspoken personal knowledge and experiences.

Finally, it's well worth being reminded that while we as human beings are always already a *quantitative* resource, we are also always and already

resourceful: we as human beings have *qualitative* resources from which to draw. I'm not referring here to our abilities to be enterprising and entrepreneurial, but rather our capacity to be brave. To be compassionate. Sympathetic and empathetic. Defiant and angry. Our ability to make use of our physical, psychological, emotional, and spiritual reserves. To be imaginative and creative, to resist, to be resilient. We have the wherewithal and preparedness to take up arms against the slings and arrows of our own body turning against itself uncontrollably. And, given our fragilities and our vulnerabilities as human, all too human, Tom Corby's *Blood & Bones: Living with Cancer* really is a most empowering affirmation of our capacity to endure.

★

1. The exhibition is accompanied by a series of public engagement activities which include artists' talks and curators' talks at The Street Gallery, public-facing and closed workshops for patients and clinicians at the Wellcome Collection and the University College Hospital Macmillan Cancer Centre, and an event at UCL entitled 'The Human, Data, and Exhibitionary Cultures'.
2. 'Human Resources: Whither the Human?', a conference I organised on the human as a quantitative-qualitative resource took place on Friday 20th April 2018 in Medical Sciences, UCL.
3. See Esther Leslie, 'This Other Atmosphere: Against Human Resources, Emoji, and Devices', *Journal of Visual Culture*, 18/1, forthcoming April 2019.
4. Herophilus's dates vary, and I chose to use those offered by the Science Museum.
5. Galen, it turns out, had been restricted to dissecting Barbary apes, not humans, since

human dissection was forbidden, and, it turns out, not all of his discoveries 'translate' precisely from one mammal to another.

6. This was the subject of my exhibition 'How We Became Metadata' at Regent Street Gallery, University of Westminster, 9th June - 5th September 2010.

7. See John Naughton "'The goal is to automate us": welcome to the age of surveillance capitalism', *The Observer*, 20th January 2019; and Shoshana Zuboff, *The Age of Surveillance Capital*, London: Profile Books, 2019. On 'algorithmic governmentality', see Tyler Reigeluth, 'Why data is not enough: Digital traces as control of self and self-control', *Surveillance & Society*, 12/2, 2014, pp243-54, and artist Zoe Beloff's 'Emotions Go To Work': <http://www.zobeloff.com/emotions/index.html>

8. For a more positive 'take' on self-tracking, selfies, etc., see for instance Lee Humphreys, *The Qualified Self: Social Media and the Accounting of Everyday Life*, Cambridge: The MIT Press, 2018, and Deborah Lupton, *The Quantified Self: A Sociology of Self-Tracking*, Cambridge: Polity Press, 2016.

**Tom Corby** is an artist, academic and writer concerned with exploring relationships between natural environments, and social phenomena. He works collaboratively with scientists and technologists, recently with the British Antarctic Survey, BBC and the Oxford Internet Institute looking at climate change and geographies of conflict respectively. Tom has a long-standing interest in how creative practitioners explore the use of data as a social, environmental and political medium. His work has been exhibited at numerous festivals, galleries and museums including: The Institute of Contemporary Arts; Victoria & Albert Museum; Arts Catalyst, Tate Online; Tokyo Metropolitan Museum of Photography; Transmediale; ZKM, ISEA; Ars Electronica; the Madrid Art Fair, and the Intercommunication Centre Tokyo (ICC) amongst many others. Reviews include: *Art Review* (2009, 2000), *La Repubblica* (2010), *Art Monthly* (2007), and *Artist Newsletter* (2006). For further details see: [tomcorby.com](http://tomcorby.com).

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**Agnese Reginaldo** is an art historian, curator, and art educator whose work focuses on the intersection between art and well-being. She works in collaboration with artists, academics, and galleries, as well as bigger institutions, with the aim of creating a more effective connection between the public and contemporary art through workshops and other types of public engagement activities. Agnese currently works at Wellcome Collection, focusing on art and mental health.

**Dr Marquard Smith** is an academic, curator, Founder and Editor-in-Chief of *Journal of Visual Culture*, and a Board Member of Arts Catalyst and the Live Art Development Agency. He's also Program Leader for the MA Museums & Galleries in Education at UCL Institute of Education, London, and Professor of Artistic Research at Vilnius Academy of Art, Lithuania. As a curator, Marq's exhibitions include 'Solitary Pleasures' (Freud Museum, 2018), 'How to Construct a Time Machine' (MK Gallery, 2014) and 'How We Became Metadata' (2010).

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